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SUMMARY OF THE SECOND TECHNICAL ADVISORY COMMITTEE MEETING

"STUDY OF THE POTENTIAL IMPACT OF THE DEFINITION RECOMMENDED BY THE NATIONAL TASK FORCE ON THE DEFINITION OF DEVELOPMENTAL DISABILITIES"

H.E.W. CONTRACT NO, 105-78-5003

SUMMARY OF THE SECOND TECHNICAL ADVISORY COMMITTEE MEETING

Ramada Inn, Rosslyn (Arlington), Virginia
June 11 and 12, 1979

Present:

Members: D. Bebee; E. Boggs; J. Dempsey; J. Drage;
M. Fithian; R. Gettings; D. Heppel; S. Katz;
N. Lourie; R. Varela (representing F. Bowe)

Staff: E. Beard; E. Gollay; N. Houston; S. Jacobson;
K. Lapidus; W. Morgan; V. Nelkin; E. Sobel

Federal: K. Rogge; M. Kapp; L. Haber

Absent: A. Halpern; M. Kirkland; P. Magrab, members

The meeting was chaired by Elinor Gollay, Principal Investigator for the project. The key items discussed are summarized below.

1. Introduction of the participants and review of the Agenda (Attached)

2. Review of Progress to Date

Project staff reviewed the progress of the DD Definition Impact Study project for the Committee. Clarification was made of the purposes of the study. This project is apparently not the "report to Congress." Project staff are still waiting to hear if they will be funded to perform the additional tasks. The field studies are progressing well and two site visits have been completed: Massachusetts and Michigan. Project staff will prepare documents based on these visits.

Communication with the Advisory Committee and other interested parties has included the revised initial issue paper, summary of the first TAC meeting, and the first newsletter.

The description of the DD population is underway, and documents related to the projections were distributed.

The proposed operational definition, which goes beyond the scope of the original contract, will prove useful for both service providers and planners. It is important to describe functional limitations that tell about service needs in order to plan. Thediscussion centered around using existing data, and making reasonable approximations. The first cut at operationalizing functional limitations is reflected in the materials distributed by Elinor Gollay and Eugene Sobel, who have been working on the population tasks.

3- Discussion of Field Studies

The field study consists of site visits to a number of states to gather information in as much detail as possible regarding the impact of the new definition of developmental disabilities. The field teams are interested in the various actors in the state DD programs and what, if any, changes are taking place or are anticipated.

The staff had developed guide questions to ask during interviews of state personnel, and developed research guides for each component of the DD system to be visited:

- The DD Planning Councils
- The Administering Agencies
- Cooperating Agencies
- Providers
- Consumers
- Protection & Advocacy Systems (P&A)
- University Affiliated Facilities (UAF)

Contact was made with the Directors of the DD Planning Councils in Massachusetts and Michigan, the first two states chosen. The Directors arranged appointments for the two field study teams (Elinor Gollay and Valerie Nelkin, Massachusetts; Solomon Jacobson and Carolyn Levin, Michigan) during their three day visits. Response was good and much information was gathered. Three time periods provide a framework for the site interviews:

Past	Present	Future
Period of November, 1978 (as of time Act Passed)	Since passage of New Act	Up to 2-3 years from now

The intent of the field study is to determine the following:

- critical points of change
- directions of changes
- responses to changes
- strategies for mitigating problems

Possible changes may be in the composition and function of the DD Planning Councils, in the participation of cooperating agencies, and in the status of the original "Big Four" advocacy groups (MR, Cerebral Palsy, Epilepsy, Autism). As a result of the study the staff hopes to describe what is happening at the State level, point out the amount and kind of technical assistance needed, specify the definition in order to make it operational; and detail costs involved.

Valerie Nelkin presented the site report on Massachusetts and Solomon Jacobson presented the Michigan site report. A summary of these reports may be found in the Appendix. The overall issues from the site visits include the following:

- Questions concerning Council membership (Who i Developmentally Disabled? How will that decision be made and by whom? How will the mentally retarded be represented?)
- The relationship between the DD Council and Vocational Rehabilitation. (Will the two agencies work closer together?)
- Planning and services for children and/or adults
- Use of the definition by providers and by planners
- Links with other systems e.g. transportation
- Focus on medical aspects of disability and implications for health insurance related to the concentration on the more severely physically disabled
- Emphasis of Protection & Advocacy Systems especially with regard to P.L. 94-142
- Are new persons being served or are individuals merely being re-labeled?
- Access to DD services for all handicapped
- The relationship between the new DD definition and Section 504 of the Rehabilitation Act of 1973
- Privacy and confidentiality concerns of Developmentally Disabled individuals
- Application to very young children, especially with mandate on prevention/ early intervention
- Continuity for client (If client improves, is client no longer DD?)
- Parental representation on the DD Council
- Consistency of eligibility criteria across various programs

- DD Population Boundaries: (What lies inside, what falls outside? Can states serve less than, or more than,the total DD population?)

- To what extent are the chronically mentally ill being served in DD programs?

- The relationship between DD and Title VII regarding eligibility criteria (no age of onset in title VII)

- The interpretation of very severe functional limitations in one area (e.g. deaf). (Is this person Developmentally Disabled?)

- Identification of those most at risk of becoming DD without intervention

- The mildly handicapped—will they now be overlooked?

Review of Methodology

The field study procedure for the project includes site selection; preparations for site visits; meeting with DD Council staff and other agencies; transcribing interviews, and writing reports. The final case studies will be sent to the Executive Directors of the Councils who will make them available to other interviewees, after verifying the validity of the reports.

The impact variables concerning the new DD definition, both internal and external to the DD System, were discussed by TAC members. Internal variables include issues such as Council membership and allocation of DD funds. External variables include issues such as relationships among agencies, and the inclusion of the chronically mentally ill or other groups. A TAC member suggested examining what happened when Autism was added to the DD definition in 1975.

Impact Variables - New DD Definition

The following impact variables were listed and discussed by TAC participants:

Variables Internal to DD Program:

- Membership on DD Council
    - -Consumer Representation
    - -Agency Representation

-Allocation of DD monies—Priorities

- Extent of Council's knowledge of new disabilities
- Eligibility for recipients of DD services
- Council staffing needs
- DDPC structure and organization
- Legislative impacts
- Executive Orders - Are changes needed?
- Locus of the administering agency
- Are grantees likely to change?
- Monitoring activities/evaluation activities of DD Council
- Planning activities of DD Council
- Expertise in assessment/evaluation of functional impairments
- Leadership role of DD Council
- Description of the DD Population (who is in, who is out)
- The use of self-description by Developmentally Disabled individuals for eligibility purposes
- Labeling - Are new labels being created?

Variables External to DD Program:

- Relationship with Vocational Rehabilitation/ Title VII (Comprehensive Services for Independent Living P.L. 95-602)
- Use of Title XIX
- Relationship with Mental Health groups
- Relationships with advocates for the deaf, the blind, and other disability groups
- Organization/Structure at the State level
- Implications for the mildly handicapped
- Voluntary sector-organizational aspects/ consortia

- Relationship with Protection & Advocacy Systems
- Methods of outreach/explaining new definition
- Legislative/policy changes
- Costs of the change in the DD Definition

Continued discussion of field studies

The original plan called for site visits to six states, and telephone discussions with representatives of states not visited. An alternative was suggested of visiting four states for indepth interviews with additional "mini studies" of other states.

Massachusetts and Michigan have been completed; other potential states to be studied include Texas and/or California, South Dakota or Montana, Oregon, Puerto Rico or Hawaii, and Georgia or West Virginia.

4. Population Implications

A number of documents relating to the DD population were distributed to the attendees. The following materials were distributed at the Technical Advisory Committee meeting:*

The Survey of Income and Education as a
Source of Population Estimates of
Developmental Disabilities

Form SIE-1 Survey of Income and Education Dept. of
Commerce, Bureau of the Census

Some Issues in Estimating the Size of the
Developmentally Disabled Population

Packet of Materials on the New Developmentally Disabled
Population: Conditions, Functional Limitations, and
Service Needs:

(continued)

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*It should be noted that some of the materials distributed to the Technical Advisory Committee were developed in part under a separate contract being conducted by Bron Cleveland Associates, with Gollay & Associates as a subcontractor, for the Governor's Council on Developmental Disabilities in Illinois. This other contract has provided a State-specific perspective and an opportunity to test the applicability of certain materials in a State context.

I An Outline of Conditions that May Result in a Developmental Disability

II A List of Conditions and Impairments that Might Lead to a Developmental Disability

III Links Between Conditions and Likelihood of Substantial Functional Limits

IV Definitions of Functional Limitations for Developmental Disabilities

V A Suggested Taxonomy of Services for Developmentally Disabled People

VI A Framework for Matching Functional Limitations and Service Needs

(All information provided in these materials is in draft form and should not be quoted or reproduced,) The use of the Survey of Income and Education (SIE) (U.S. Dept. of Commerce, Bureau of the Census) data as a source of population estimates of developmental disabilities was discussed by participants.

One way to describe the DD population is by using specific conditions, and building up from there. Also, how likely are certain functional limitations to result in which services? The discussion centered on describing the population through the following progression:

Condition—Functional Limitation—Service Needs—Likelihood of being met

One TAC member suggested that an important determinant in describing the DD population is time since onset (of the disability). The further away from the time of onset the less chance there is of remediation by technology. That is, change capacity decreases with time. Age of onset can be used as a classifier and enables the focus of resources. Time since onset has direct bearing on service needs. Services may be primarily supportive, or medical. There are probably a significant number of conditions that, if treated adequately with technical services, would likely not be DD.

Participants also discussed classification of mental disorders, especially the determination of which childhood conditions lead to chronic conditions. It is, of course, easy to abuse a list of conditions. Also, languages of description vary widely. Communication with others using the same language is important.

The following purposes/aspects of Data Collection were listed by TAC participants:

1. List of descriptive and analytic variables
2. Operational definition
   - —For Research and Statistics purposes
   - —For Diagnostic purposes
3. For use by policy makers—consider ramifications in terms of categories
4. Politics and planning are difficult to separate

Continuation of Population Discussion

An Advisory Committee member pointed out that we must recognize political realities and that our judgements in deciding functional criteria and types of services are compromise judgements. It becomes a matter of one cutoff vs. another. The way to get out of this situation is to make the best judgements we can, protect the political aspects, and build in the ability to add a quantitative dimension (e.g. to conditions). We can make two statements about cutoffs, offering information about both, so that the options can be known.

Two available cutoffs:

- Activities of Daily Living—Use functional criteria
- Conditions—List specific conditions but recognize the limitations.

For accountability purposes, using two cutoffs can provide a look at the population through both paths, with some flexibility in the classification system.

The TAC feels that labelling issues and political realities remain crucial aspects of the process of identification. Constituency group motivations involve existing programs, the discrimination felt by certain subgroups, and the interaction between parents and physicians regarding specific diagnoses.

Another important element is what to do with the outcome of the population study and how to present it. Different audiences for the population products and the operational definition include planners, politicians, providers, and consumers. TAC suggestions on presenting information to politicians/legislators:

- Do not go into technical details; use simple terms
- Summarize for legislators
- Introduce concepts of severity and chronicity

Much discussion and disagreement followed on the system of classification of DD, the relationship of this to the definition and to planning purposes. The following were TAC suggestions/additions to project materials:

Additional Indicators for Functional Limitations

(Note that major residual disability can be prevented with appropriate medical intervention at the right point in time.)

Chronicity

A. Short term—acute (minimal residual effects)
B. Terminal before 6 years
C. Terminal before 22 years
D. Likely to last indefinitely

Probability, Likelihood

A. High, medium, low
B. Ask for precise percentage, then cluster
C. Take actual incidence rates and see how they cluster

Consensus :

A. Send materials to TAC members and others
B. Focus on non-low incidence; high likelihood; then look at jurisdiction
C. If look at responsibility will have major state variations
D. More useful to indicate services needed
E. Differentiate between developmental disability and developmental disorder

Continued Discussion of Population Documents Distributed

Discussion centered on the best use of the population materials. The following are TAC suggestions for additions, deletions and notations:

Documents I and II (Conditions)

- Add "head injuries"
- Note difference in probability of recovery
- Add another column for the etiology

Document III (Conditions and Likelihood of Limitations)

Add conditions
Add"high prevalence"; "high likelihood"

Document V (Taxonomy of Services)

- Use the existing list of services in plan
- Do not need extremely specified list
- List functional limitations and most relevant services
- Use GSS (Government Services & Systems) list of taxonomy and groups services

The participants agree that the overriding concern is to employ the format that makes the most sense—and to do the tasks in a manner that will be useful to the States.

Sources of Data/Data Issues

Major data sources for the population estimates were discussed at length by project staff and TAG members. Many data tapes are available to the public. The principal data source to be used for this study, the Survey of Income and Education (SIE) was reviewed. SIE data are available for each state.

Further discussion of data issues, including data limitations and potentials, included the following items:

- Need estimates of the extent of underreporting of specific conditions:
    - Mental Illness and Mental Retardation are considered to be underreported
    - Children's handicaps are considered to be underreported
- Self reporting of disability vs. proxy reporting of disability
- Explanation of limitations should be included with population estimates
- See Canadian National, Health Survey and Kalimo survey from Finland for current information; also see Survey of Care with major international comparisons by Kohn & White
- Consider the potential misuses of statistics
- Children with mild limitations may be overlooked
- Compare data with P.L. 94-142 data
- Some DD Councils are using National figures/ estimates for DD population

- The effect of capacity for self-direction and self-care on independent living
- The use of "independent living" with children: The need to eliminate younger ages for independent living category
- Judging learning difficulty in adults: a difficult task
- The need to obtain information that is appropriate for a given age level for clinical decisions

The following potential data sources were listed by staff and TAC members:

1. Survey of Income and Education (especially ages 14-25)
2. Social Security Administration surveys
3. Social Security childhood disability
4. P.L. 94-142 data
5. Supplemental Security Income data
6. Data based on major conditions likely to contribute to DD population
7. Surveys from other countries
8. Survey of institutionalized persons and National Institute of Mental Health data
9. University of Minnesota surveys
10. Some birth cohort studies
11. Maternal and Child Health/Crippled Children's Services data
12. Foundation for child development

Major Sources

5. Operationalizing the Definition

Participants discussed identifying the key uses and describing methods for operationalizing the definition. The operational definition, an important outcome of the study, will be designed to be used by planners, service providers, and advocates for the disabled. After procedures for operationalizing the definition are identified, operational questions for planning and programmatic purposes will be developed. Guidelines for dissemination to State officials, including basic screening questions, will be available at the end of the project.

APPENDIX

(DRAFT: Do not quote or reproduce)

SITE VISIT REPORTS

MASSACHUSETTS NOTE: Confidential summary observations subject to review by State officials

Preliminary Overall Impressions:

- Little dramatic impact overall in the State
- Some changes taking place in DD system, not necessarily due to new DD definition
- Many agencies feel they are already serving the "DD population" as defined in the new definition
- Anticipation of increased numbers of mentally disabled individuals desiring access to services
- Increasing emphasis on serving the more severely handicapped
- State officials feel that criteria for "functional limitations" and "significant impairment" are lacking

Places Visited:

Massachusetts DD Council
Administering Agency (Office of Secretary of Administration and Finance, Bureau of Systems Development)
University Affiliated Facility
Medicaid
Epilepsy Society and United Cerebral Palsy
DD Law Center (P&A)
Department of Mental Health/Mental Retardation
Special Education
Massachusetts Rehabilitation Commission
Federation for Children with Special Needs
Regional Representative

Information Gathered:

- No state DD legislation
- Massachusetts DD Council established in 1975 by Executive Order of the Governor

- Fairly extensive service network includes:
  - Department of Mental Health
  - Department of Public Health
  - Department of Public Welfare
  - Massachusetts Rehabilitation Commission
  - Massachusetts Commission for the Blind

Additional agencies with some reponsibility to DD population:
Department of Education
Department of Elder Affairs
Department of Community Affairs

- Major private advocacy organizations
  - Epilepsy Society
  - Association for Mentally Ill Children
  - Massachusetts Association for Retarded Citizens
  - United Cerebral Palsy
  - National Society for Autistic Children
  - DD Law Center

- Population

  About 263,000 DD

  1.46% substantially disabled (from State Plan)

  Prevalence rate based on national figures

- Council
  - 36 members
  - Three slots to fill to achieve 50/50 consumer quota
  - Major area of Council coordination=Section 504 implementation
  - More attention to the more severely handicapped
  - Substantial disability or limitations is being determined by self-description
  - DD Council would like other agencies to "open up" more to the DD population

- Cooperating Agencies
  - Some see a great increase in the population
  - Concern about having to share benefits with new groups due to broadened population

- The DD Council and Administering Agency and DD Law Center see a greater need for outreach into the community as a result of the new definition

- Concerns/Problems

1• Council representation/membership
   - What is a consumer? Who is Developmentally Disabled?
   - How can Councils get a broader base of disabilities without going into specific categories?
   - Will the effect of 50% consumer representation compromise state agencies?

2. Concern about greater numbers to serve with inadequate funds (= less for all)

3- P.L. 94-103 was barely off the ground when it was changed

4. Criteria for functional limitations and significant impairment are unclear

5. The future of DD is uncertain

- Need for Technical Assistance
  - Little Federal Assistance received
  - "Wait and see" attitude
  - A need for National direction

MICHIGAN NOTE: Confidential summary observations
subject to review by State officials
(DRAFT: Do not quote or reproduce)

Preliminary Overall Impressions:

- Limited initial impact of new definition

- Increasing role of mental health services within DD field

- Split in level of concern about the new definition
  Greater concern on planning level; presents data problems
  Less concern among providers; appears to be useable

- Some feeling by participants that new definition has involved political implications and may result in relabeling

- If new definition moves toward serving chronically ill population,it may alter staffing patterns

- Time frame not realistic—Introduction of new definition will take longer than anticipated.

Places Visited;

DD Planning Council
Administering Agency (DD Services Unit within Dept. of Mental Health)
Vocational Rehabilitation (by telephone)
Special Education ,
Dept. of Public Health
P & A system (operated by Michigan ARC)
UAF (by telephone)
Three consumers
Community Mental Health Program

Information Gathered;

- No state DD legislation
- DD Planning Council established by action of Governor; is located administratively with the Dept. of Mental Health—but is physically separated, and the DDPC is semi-autonomous
- DD population=400,000
  Target group=4% of population
- Active service network includes the Departments of Social Services, Mental Health, and Education
- Major goals of DDPC include planning and coordination, diagnosis and evaluation, and activities of daily living
- DD Council is taking a more active role legislatively
- DDPC is not particularly concerned about the impact of the new definition on Council membership
- DDPC would like to see an operational definition; Council is waiting for Federal assistance
- Would like to include the definition in the special education area
- Interest expressed by some interviewers on what happens to the DD person over age 26
- Future role of mental health in DD program considered an important factor by most interviewers
- Concern was expressed over demand for services by emotionally impaired individuals

Attempt to adopt a uniform assessment device (adaptive behavior scale) sparked a legal battle and temporarily inhibited use of uniform data instruments

Vocational Rehabilitation, located in Education Department, will probably shift; move from 18% to 40% severely disabled population

Expected increase in participation of bidding for DD grants within the State

Slow introduction of new definition; not much concern of implications expressed by interviewees who claimed that a functional approach was already, de facto, in place in the State